RR Registrar Review

Vol. 4, No. 1 **Quarterly Newsletter of the Virginia Cancer Registry** **Spring 2000**

Welcome to the Spring 2000 edition of the REGISTRAR REVIEW (RR), the quarterly newsletter of the Virginia Cancer Registry (VCR). We remind all readers of our aim that the content of this newsletter address current and changing needs of cancer control and prevention stakeholders in Virginia. Therefore, we welcome any and all comments, criticisms and suggestions on how the RR can continue to meet the dynamic needs of Virginia's cancer reporting system. If you have comments, please do not hesitate to let us know by contacting the VCR at:

Virginia Department of Health
Virginia Cancer Registry
P.O. Box 2448, Room 114
1500 East Main Street
Richmond, VA 23218

(804) 786-1668 phone
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VDH VIRGINIA DEPARTMENT OF HEALTH
Protecting You and Your Environment
www.vdh.state.va.us

VCR Patient Notification Law

On July 1, 2000, a new law will go into effect requiring the Virginia Cancer Registry to develop a system to notify each patient reported under § 32.1-70 of the Code of Virginia. This law resulted from House Bill 603, introduced on behalf of a cancer patient concerned about the perceived secretive existence of the statewide cancer registry. The Bill came after over one year of discussion and legislative study about the VCR, its role in cancer control and prevention, and its effectiveness.

In essence, within 30 days of receipt of a report for a new patient, the VCR must send that person notice of the report, his or her rights under the Privacy Protection Act, and basic information about the VCR and its functions.

While the VCR will be doing the notification, this new activity may have ramifications for reporting facilities and physicians as well. Many cancer programs have debated the merits of notifying their own patients of the hospital cancer registry. When the VCR's notification process begins, those registries should be prepared to step into the public's awareness too.

You will receive more information in the coming months as we implement this system. In the meantime, if you or your hospital cancer committee or administration have any questions about the new law or its implementation, please call Amy Pugh at (804) 786-1668. (*See page 2 for the full text of the new law.*)

In This Issue:

Below is the text of HB603, which will become effective July 1, 2000.

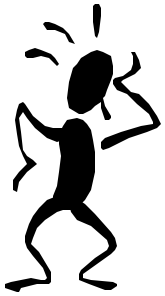
Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia is amended by adding in Article 9 of Chapter 2 of Title 32.1 a section numbered 32.1-71.01 as follows:

§ 32.1-71.01. Notification of cancer patients of statewide cancer registry reporting requirements.

The Commissioner, or his designee, shall develop and implement a system for notifying, within thirty days of receipt of the case record, each patient whose name and record abstract is reported to the statewide cancer registry pursuant to § 32.1-70 that personal identifying information about him has been included in the registry. The notification shall include (i) the purpose, objectives, reporting requirements, confidentiality policies and procedures of the statewide cancer registry, including, but not limited to, continued surveillance and investigation procedures and (ii) a copy of § 2.1-378 of the Privacy Protection Act.

2. That the Board of Health shall promulgate regulations to implement the provisions of this act within 280 days of enactment of this provision.



Common Errors Cause Big Headaches

Dianne Collins, RHIT, CTR

Well, here I am sitting on the other side of the fence, so to speak, having left the trials and tribulations, as well as joys (?), of being a cancer program coordinator/ registrar at a local hospital here in Richmond and being the newest member of the Quality Assurance team. After spending two years working in the cancer registry, I thought I knew it all, especially the coding rules that were set forth in our "old faithful," ROADS Manual. Well, pride goeth before a fall, so the Bible says, and I am a bit more humble now than when I first appeared on the scene. I'm not feeling too terribly bad about the whole situation right now, because since I have been here at the central registry, I have found out that a lot of you folks out there were in the same boat, especially on some very simple, but often miscoded data fields. And, to tell you the truth, if we paid a little more attention to the "story" in each patient's medical record that we abstract, following events logically and in a time sequence, some of these errors just wouldn't happen (hopefully).

Like, for instance, radiation and surgery treatment dates. Not much to figure out here, January comes before December and 1998 comes before the year 2000. And, speaking of dates, there have been a lot of cases sent in without a date of encounter. Makes you wonder just how you found out about the patient in the first place, and besides, the VCR must have an encounter/admission date. When you have a patient that was never an inpatient at the time of abstracting, code 0's all the way across the date of discharge field and 9's for date unknown. That doesn't make a lot of sense, but that's what the ROADs says to do,…no "creative coding" allowed. And, explain to me just how we don't' know the tumor size (coded "999" mm) but we can put down a clinical/path T size. Oh, I suppose the doctor could just go ahead and stage the patient without knowing exactly what the primary tumor size is, but how about indicating that in the text….after all, you might wonder at some point in time just how that tumor staging was derived too.

And, it seems that this business of "recurrence" can cause some problems…like date of recurrence when no recurrence or never disease free is the situation. You can always pick up the ROADS and look this up, it's not always a logical answer, but the software programs know how to figure it out. Those pesky institutions referred from and to, are they ever a persistent example of creative coding…..use only 0's if there is no referred from/to facility, and 9's if you don't know. Other than institution ID numbers, 0's all the way across and 9's all the way across, nothing else works…doctor's numbers are not acceptable, another case of "creative coding".

And, those unknown primaries. The doctors don't like them, the registrars don't like them, and most of all I am sure the patients don't. But, they exist, so why not code them the way "old man ROADS" says…like 99-99 for nodes examined/positive, summary staging to unknown, and sites of mets to unknown. Surprisingly, this makes sense, after all, if you don't know where it came from, you can't know just how far it has gone…And, finally, those lymphomas. Just figuring out their histology coding is a challenge, but checking the summary staging can be really tricky when there is no text to indicate some of the symptoms and radiology findings that are such a big factor. Finally, in staging, watch those 88's and 99's and X's. 88's are for no staging schemes, 99's just mean there's just not enough information. Now, that's obvious, right?

Well, that's it for now. Hope these little reminders help you some and keep your chin up: remember, think about the logic of what you're saying in your abstract and remember to check things out with the Roads more often. And, finally, remember it could be worse, I could be sending these errors back for YOU to correct!!!!

Collaborative Stage Task Force

Dawn Hawkins, MS

In response to concerns about the differences between cancer staging systems, the Collaborative Stage Task Force was established by the AJCC in cooperation with the SEER program, the Centers for Disease Control and Prevention and NAACCR. Stephen Edge, MD, FACS, the task force chair, presented an update on the task force at the annual NAACCR meeting in April.

According to Dr. Edge, the task force has determined that the cancer surveillance community would best be served by replacement of the current data elements for cancer staging with a uniform data collection set. Using a computerized algorithm, Summary Stage, Extent of Disease (EOD) and Tumor, Node and Metastasis (TNM) could be derived from the data set.

The proposed data set should result in a reduced workload for cancer registrars because they will be collecting a single data set under a single set of rules. Breast, prostate, colon, and rectal cancer data sets have been created and are currently being pilot tested. In June, work will begin on developing data sets for the digestive system, gynecologic, and genitourinary cancer sites.

Implementation of the new uniform data collection set is planned for January 2003. For more information, refer to Dr. Edge's article in the May 1999 issue of the Journal of Registry Management, or point your browser to www.cancerstaging.org/initiatives.html.

Check your Mailboxes!!!

In the next few months, the VCR will fill your mailboxes with several reports. In June, we will mail out the long-anticipated 1995-1996 incidence report. In July, we will mail out the latest site study, "Prostate Cancer in Virginia, 1970-1996." Later this fall, the 1997 incidence report will be ready to distribute. Please take a moment to look over each of these reports, and send any comments or feedback to the statistical analysis team. This is your cancer data in action!

National Melanoma and Skin Cancer Awareness Month

Dawn Hawkins, MS

May is National Melanoma and Skin Cancer Awareness Month. This month is dedicated to raising public awareness of skin cancer prevention, early detection, and treatment. Each year 1.3 million Americans are diagnosed with basal cell and squamous cell carcinomas, highly curable forms of skin cancer. Another 50,000 Americans are diagnosed annually with melanoma, a far more dangerous form of skin cancer. The American Cancer Society estimates that in Virginia this year, 1,200 individuals will be diagnosed with melanoma.

Skin cancer is largely preventable when protective measures are consistently practiced. Unfortunately, approximately 50% of American adults do not practice such measures. Exposure to ultraviolet (UV) rays appears to be the most important preventable factor in the development of skin cancer. To protect yourself, avoid excessive exposure to the sun and other sources of UV light, such as tanning booths and tanning lamps. If you are outdoors, protect your skin with clothing, including a shirt and a hat with a broad rim, and be sure to wear sunscreen with a SPF factor of 15 or more on all areas of exposed skin.

The "ABCDs" are a simple way to remember the four basic warning signs of a melonoma: Asymmetry, Border, Color, and Diameter. Assymetry—melanomas are generally asymmetrical, while healthy moles are round and symmetrical. Border—melanomas often have notched, ragged, or uneven edges, while healthy moles have smoother, more even borders. Color—melanomas often have varied shades of black, brown and tan (red, white and blue may appear in later stages), while healthy moles are usually a single shade of brown. Diameter—early melanomas tend to grow larger than healthy moles, usually larger than the size of a pencil eraser. Talk to you doctor if you notice any of the warning signs of a melanoma or any other changes in the size, shape or color of a mole.

The Graph of the Quarter (page 6) shows where on the body melanomas tend to develop. Also, more information about melanoma in Virginia can be found in the VCR publication, Melanoma in Virginia, 1970 - 1996.

NAACCR Registry Workshop Worth the Ordeal

Dianne Collins, RHIT, CTR

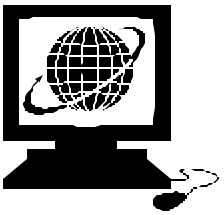
Taking the train instead of flying to Claymont, Delaware sounded great to me, who is someone who measures flight distance in the number of martinis one can down between take-off and landing time. I just didn't plan on having to handle my own luggage, 3 densely packed overnighters and one purse the size of a footlocker. Being the well prepared person I always am and thinking ahead, I carried 4 books to read on the train, four books that I couldn't get to even look at because they were piled under the rest of the luggage and the zipper was stuck anyhow. If I had forced the zipper, not only could I have gotten to the books, but I could've shared my underwear with everyone on the train. And, traveling with my coworker, Jayne Arline, who was 5-6 months pregnant also added excitement to an otherwise routine training trip. Luckily, her mom came along, so I figured I'd have immediate assistance if the newest addition to the QA team decided to show up on the scene unexpectedly. The train trip, otherwise, turned out to be a pleasant experience: I didn't have to worry about whether the engines were going to fail or if we had a terrorist on board and would land in Cuba instead of Delaware, so that was definitely a plus. So, once we ended up in Claymont (where is Claymont anyhow?), we rented a car (too small, but it was the best Hertz could do for us) and headed to our motel. The rooms were pretty nice if one doesn't mind sleeping with the bed sheets creeping up off the sides of the bed, and getting locked out twice because the "new electronically programmed" doorkey system didn't work.

Well, after all that, we finally did manage to make it to the workshop where we participated in lively and stimulating dialogues and problematic exercises on case ascertainment (that's "case finding" to you newcomers). We also were instructed in methods of followback and death clearance, comparison of AJCC and Extent of Disease staging systems, the art of abstracting, and data quality reviews. Despite our plans to see the world-renowned night life in the town of Claymont, we were assigned homework which was dutifully, but sulkily, completed.

I must admit the most entertaining part of the trip was having 20 minutes for Jayne and her mom to change their train schedules and head home with me after the last discussion on Friday. Seeing a woman in the full bloom of pregnancy rushing around turning in rental cars and dragging luggage in a rush to board a train is not a pretty sight, believe me, and I must admit was I relieved to see her finally settle in on the southbound car with everything intact…and I do mean *everything*. I arrived back at the Fredericksburg station early in the evening, better versed in registry management and looking forward to using those newly acquired skills, and even happier to see Jayne still in one piece, so to speak, on that following Monday.

As I look back on the experience now from the comfort of my desk, I can well appreciate, despite the ordeal, the opportunity to meet with other central and hospital registrars from all over the country. Sharing experiences, humorous stories, solutions to problems and different perspectives, as well as the in-depth coverage of many aspects of registry management, e.g., case-finding, extent of disease, multiple primaries, was well worth the whole episode, and here it is the end of May, and Jane is still hanging on, so next time I travel, I think I'll just put on that famously silly grin and say, "What, me worry?".

Another Internet SSDI Source



Although it isn't as fancy as the **www.ancestry.com** site, here is another free source for checking on deceased cancer patients through the Social Security Death Index. A brief comparison seems to show identical results, but one site may be faster or may be accessible when the other is not.

http://ssdi.geneaology.rootsweb.com

Death Clearance Process Underway (Finally!)

Many of you are aware the VCR has begun researching cancer deaths to patients not registered in our database. You also are probably aware that we have not perfected the process!

Over 13,000 Virginia deaths occur each year with cancer listed as a contributing cause. The VCR uses a combination of automated and manual procedures to compare these deaths to the patients already listed in our files. Unfortunately, sometimes we do not catch all matches and mistakenly think a person with a cancer-related death had never reported to the VCR. We are sorry if you have received such a report, but please bear with us as we improve the way we link to the computerized death certificates. **(Continued on page 5)**

This follow-back process is critical for a more complete assessment of cancer incidence and survival among Virginians. We must contact the facility of death or reporting physician to verify the diagnosis and obtain more information, such as date of diagnosis, residence at diagnosis, and treatment received. Without this basic information, the person can only be registered as a "death certificate only" case, since that is the only source of information on the person's cancer. As you can imagine, that means a very limited cancer abstract, which has limited use for cancer control and prevention planning!

Roughly 40% of cancer deaths in Virginia occur in a hospital, so cancer registrars and medical records staff are our primary contact for these patients. Since hospitals don't always have the necessary information, however, sometimes we will need to make a secondary contact with attending physicians, etc.

We are grateful for your patience as we work to streamline our process and clarify our requests to you for information. Thank you also for the timely manner in which we have received responses, and as always, thank you for helping to keep our information as current, complete, and accurate as possible.

VCR Goes National!

Last month at the annual conference of the North American Association of Central Cancer Registries (NAACCR), staff of the Virginia Cancer Registry were responsible for two oral presentations and seven poster presentations. Topics included:

- Patient confidentiality concerns
- Estimating case completeness
- Differential prostate cancer ascertainment
- Effect of geocoding on incidence rates
- Monitoring data requests and usage
- Effect of changing population sources
- Melanoma in Virginia
- Laryngeal cancer in Virginia
- VCR participation in statewide cancer control planning

Handouts are available for some of these presentations; please contact the VCR if you would like more information.

Incidence Reporting

Jayne Arline, CTR

Many of you who submit your "incidence only" cases on hard copy (paper) were made aware of how to submit these cases to the VCR at our annual conference in March. This article will reiterate that procedure for those who were unable to attend.

An incidence reporting form should be completed for each case submitted, whether clinically or pathologically diagnosed.

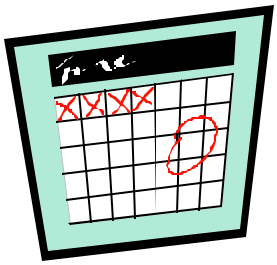
The fields that must be completed are:

- **Name**
- **Full Address**
- **Race**
- **Ethnicity**
- **Sex**
- **Date of Birth**

Treatment and **exposure history** should be completed for any type of case, if available. The tumor information does not have to be completed provided a path report is attached to the reporting form. If the case is pathologically diagnosed, a **path report** must accompany the reporting form**. If the case is clinically diagnosed,** please complete as much of the form as possible**.**

I will be going out on maternity leave on May 25, 2000; if you have any questions regarding incidence reporting they can be directed to Bonnie Perry, RHIT, CTR.

Mark Your Calendar



June 19-21 **Advanced Cancer Registry Training Program**, Atlanta, GA; registration fee $400.00: This intensive and comprehensive training program is taught by a staff of recognized experts in cancer registration, surveillance, and control at Emory University. This Advanced Cancer Registry Training Program will specifically address: abstracting, staging, and coding really difficult cancer cases; bizarre, rare, and unusual cancer cases; calculating incidence, prevalence, age-adjusted, survival, and other rates; using registry data (preparation, analysis, annual reports, etc.); and using the Internet to locate comparable data and useful cancer information and resources. Participants must have attended the Principles and Practice training program prior to registering for this a advanced training (or have at least one year of experience working in a cancer registry). For more information contact Steven Roffers, PA, CTR at (404) 727-4535, fax (404) 727-7261 or e-mail sroffer@sph.emory.edu.

July 24-28 & Dec. 4-8 **NCI Principles of Oncology for Cancer Registry Professionals,** Potomac, Maryland; registration fee $595.00; This is an intensive five-day training program in cancer registry operations and procedures emphasizing accurate data collection. The program includes extensive site-specific, hands-on case abstracting and coding sessions using both full medical records and abstracts that demonstrate the many situations registrars may face. This program is suitable for oncology program employee (hospital-based and central registry) with minimal knowledge of cancer, anatomy, physiology, and medical terminology. Cancer registrars with less than one year of experience would benefit most from this program, however registrars with up to three years experience and regisrars preparing for the certification examination are welcone to attend. Class size will be limited to 25 registrants. For further information contact April Fritz, ART, CTR, Training Program Coordinator, Data Quality Manager at (301) 402-1625, fax (301) 496-9949 or email april.fritz@nih.gov.

Aug. 14-18 & Nov. 6-10 **Principles and Practice of Cancer Registration, Surveillance and Control,** Atlanta, GA; registration fee $800.00. This program will be held on the campus of Emory University. This program is suitable for all oncology healthcare personnel, especially oncology program (hospital-based and central registry-based) employees with minimal knowledge of cancer anatomy, physiology and medical terminology. Cancer registrars, statistical staff and epidemiological staff who utilize cancer registry data would benefit most from this program. Complete details are available via their web site at http:/cancer.sph.emory.edu or contact Steven Roffers, PA, CTR at (404) 727-4535.

Oct. 19-20 **Virginia Cancer Registrars Association Annual Meeting**, Augusta Medical Center, Fishersville, VA. More information is forthcoming as to the registration fee, speakers and agenda. For more information contact Bonnie Bowman, RHIT, CTR at 540-932-4664 or Jessica Winfrey, CTR at 804-982-8127.

Exam Eligibility Questions
Contact Elaine Collins, CTR
Phone: (612) 676-5336
Fax: (612) 676-5099

CTR Examination

Examination Date	Application Deadline
September 16, 2000	August 1, 2000
March 10, 2001	February 1, 2001
September 15, 2001	August 1, 2001

Quality Assurance Q & A

Each quarter the Quality Assurance staff will provide a summary Q & A for relevant topics. As a follow-up to the two presentations at the VCR 2000 Training Conference, this first QA Q & A focuses on benign central nervous system system (CNS) tumors.

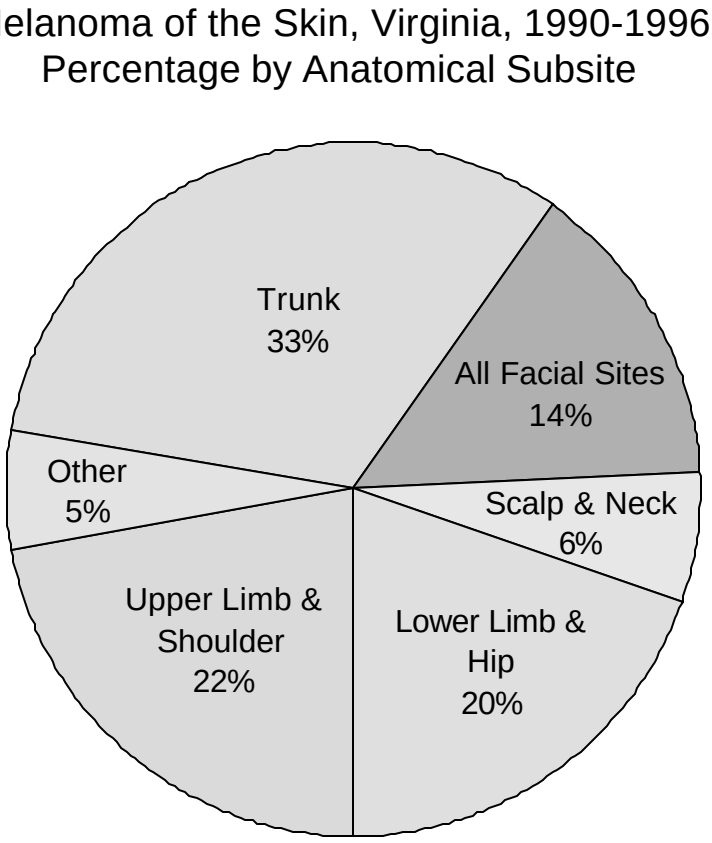
Q: What year did the Virginia Cancer Registry require the reporting of benign CNS tumors?
A: *Virginia regulations include benign CNS tumors as reportable to the VCR beginning with 1994 cases. The site and histology listing of reportable CNS tumors may be found in Appendix U of the Virginia Cancer Registry Reporting Handbook Volume I: Hospital Registries.*

Q: Does a complete abstract need to be submitted for benign CNS tumors?
A: *Yes, the VCR would like a complete abstract for all benign CNS tumors.*

Q: Does the VCR require follow-up information on patients diagnosed with benign CNS tumors?
A: *No, VCR does not require follow-up on benign CNS tumors.*

Q: Do we report the benign CNS tumors with the facility's regular submissions?
A: *Yes, please include the benign CNS tumor with your regular submissions.*

Graph of the Quarter



Note: Data included in situ melanomas. N = 5,792